Children's Special Health Care Services (CSHCS)

Local Health Department (LHD) Care Coordination Program Assessment of Health Care Transition (HCT) Activities for Youth with Special Health Care Needs (YSHCN)

FINAL REPORT

April 10, 2023

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EXECUTIVE SUMMARY

The Michigan Department of Health and Human Services (MDHHS) Children's Special Health Care Services (CSHCS) program strives to enable individuals with special health care needs to have improved health outcomes and an enhanced quality of life through the appropriate use of the CSHCS system of care. An important component of the CSHCS program is to provide Health Care Transition (HCT) guidance and support to youth and families. In Michigan, 26.7% of Children and Youth with Special Health Care Needs (CYSHCN) reported receiving services to assist with their transition to adult health care (National Survey of Children's Health, 2019-2020). While Michigan performs better than the national average, the data indicates that more than two-thirds of Michigan's CYSHCN are not receiving necessary HCT services, making them vulnerable to worsening chronic health conditions, behavioral health issues and underutilization of needed health care services.

Based on the Six Core Elements of Health Care Transition™[1],Michigan's CSHCS Program, in collaboration with staff from Got Transition®[2], developed an annual HCT assessment survey for Local Health Departments (LHDs) across the State. The goal of this first annual *2022 LHD Care Coordination Program Assessment of Health Care Transition (HCT) Activities for Youth with Special Health Care Needs* (YSHCN) survey was to acquire baseline HCT data that will be tracked annually and used to enhance CSHCS-HCT program development.

The Michigan State University Institute for Health Policy (MSU-IHP) provided technical assistance and support for this HCT assessment survey project.

In August,2022, each of Michigan's forty-five LHDs **(Appendix A)** were sent a link to the *2022 LHD Care Coordination Program Assessment of Health Care Transition (HCT) Activities for Youth with Special Health Care Needs* (YSHCN) survey tool **(Appendix B)** via email; all 45 LHDs responded to the survey (100%). Each question on the survey provided four (4) possible response levels from which the LHD could choose, Level 1 (basic) through Level 4 (comprehensive). Questions addressed the following elements of HCT:

1. Availability or adherence to a HCT Policy
2. Tracking and Monitoring HCT Activities
3. Availability or Use of Transition Readiness Assessment Tools
4. Transition Planning
5. Transfer of Care to Adult Providers

[1] The Six Core Elements of Health Care Transition™ are the copyright of Got Transition®. This version of the Six Core Elements has been modified and is used with permission.
[2] Got Transition® is a federally funded national resource center on health care transition (HCT). Its aim is to improve transition from pediatric to adult health care through the use of evidence-driven strategies for health professionals, youth, young adults and their families.

6. Evaluation of Transition Completion for Clients of Transition Completion Age

The survey also invited respondents to share suggestions or challenges they experienced related to CSHCS transition policies, documents, and trainings.

Results from the *2022 LHD Care Coordination Program Assessment of Health Care Transition (HCT) Activities for Youth with Special Health Care Needs (YSHCN)* survey indicate:

1. Overall, the average score on the survey was Level 2.23. The highest average score attained by a single LHD was Level 2.5; the lowest average score attained by a single LHD was Level 1.0.
    a. Fourteen (14) LHDs achieved an average score of Level 1 < 2 across all questions.
    b. Twenty-four (24) LHDs achieved an average score of Level 2 < 3 across all questions.
    c. Seven (7) LHDs achieved an average score of Level 3 < 4 across all questions.
2. Most LHDs reported their HCT activity related to having or adhering to a HCT policy as Level 2 (29%) or Level 3 (29%).
3. Fifty-eight percent (58%) of LHDs reported Level 2 as their current activity related to tracking and monitoring HCT activities.
4. Thirty-six percent (36%) of LHDs reported Level 2 as their current activity related to the availability or use of transition readiness assessment tools
5. Thirty-eight percent (38%) of LHDs reported Level 2 as their current level of activity related to transition planning.
6. Most (40%) LHDs reported the HCT activity related to transfer of care to adult providers as Level 1.
7. Most LHDs reported their HCT activity related to Evaluation of Transition Completion for Clients of Transition Completion Age as Level 2 (47%) or Level 1 (47%).

Additionally, LHDs provided suggestions and commentary regarding their experiences which will be used to guide future program enhancements and training. Of these, the following general themes emerged:

1. Training opportunities related to providing HCT including:
    a. Internal policies and processes,
    b. Educational and employment opportunities/resources for youth with special needs, and
    c. Age-specific guidance regarding steps toward HCT.

2. Development of tools to support HCT activities such as:
    a. A method to track beneficiary progress through all stages of HCT,
    b. Desk-level procedures to guide the transition process from beginning to end, and
    c. A step-by-step guide about what topics to address at each age and what resources should be offered at that time.

LHDs identified the following challenges encountered when delivering HCT services to CSHCS beneficiaries:

1. Difficulty engaging parents and teens in the HCT process,
2. Speaking directly with the 18–20-year-old youth because of school or work commitments, and
3. Staff case load is high, making comprehensive HCT activities difficult to accomplish.

The following reports were prepared and made available to the CSHCS leadership team as well as the individual LHDs:

1. *MDHHS 2022 Local Health Department Health Care Transition Activities Assessment Aggregate Summary,* which provides a brief overview of aggregate Survey findings. **(Appendix C)**.
2. *2022 Local Health Department Health Care Transition Activities Assessment LHD-Specific Summary* **(Appendix D)** which provides a graphic depiction of the individual LHD's reported level of activity for each of the core elements as well as a comparison with the average score reported, overall, for each question. In the interest of preserving confidentiality, these reports are identified according to a randomly assigned number instead of the name of the LHD. A *Randomization KEY* was provided to the CSHCS Leadership team.

Additionally, this 2022 Local Health Department (LHD) Care Coordination Program Assessment of Health Care Transition (HCT) Activities for Youth with Special Health Care Needs (YSHCN) Final Report is made available here and posted on the MDHHS website at Health Care Teams (Providers, LHD's & MHP's) (michigan.gov).

In the future, CSHCS leadership will use these results to guide LHD support efforts by: (1) identifying opportunities to engage and interface with LHDs, (2) collaborating with LHD staff to develop additional tools and educational opportunities to guide HCT activities at the LHDs, and (3) conducting the *LHD Care Coordination Program Assessment of Health Care Transition (HCT) Activities for Youth with Special Health Care Needs* (YSHCN) survey annually and using the information obtained in 2022 as a baseline to track improvement in LHD HCT levels of activity over time.

Introduction and Purpose

The commitment to enable individuals with special health care needs to experience improved health outcomes and enhanced quality of life through appropriate use of the CSHCS system of care is of paramount importance to those who serve this population. Providing health care transition guidance and support for youth and families is a critical component to ensuring successful transition from pediatric to adult care providers. Additionally, these services prepare capable young adults to gradually assume responsibility for making their own health care decisions.

One of the National Performance Measures (NPMs) selected by Michigan's CSHCS program is NPM 12, which identifies the percent of adolescents with special health care needs who received services necessary to transition to adult health care. According to the National Survey of Children's Health[3], 2019-2020, 26.7% of Michigan's children and youth with special health care needs (CYSHCN) reported having received health care transition services, performing better than the 22.5% national average.

Still, more than two-thirds of Michigan's CYSHCN are not receiving necessary HCT services, making them vulnerable to worsening chronic health conditions, behavioral health issues and underutilization of needed health care services. Considering this finding, the CSHCS program set the objective that ten percent (10%) of their CSHCS partner organizations will advance to the next level on the Got Transition® "Current Assessment of Health Care Activities" from their 2022 baseline year by 2025. To achieve this objective, the following interim goals were set as well as the steps necessary to achieving them:

GOAL 1: **Acquire baseline HCT data and track data annually.**

Step 1: Implement an annual electronic assessment survey to rate HCT activities for each LHD in the State of Michigan.

GOAL 2: **Utilize survey results and recommendations to enhance program development of HCT within the CSHCS program.**

Step 2: Obtain program feedback from LHDs regarding current HCT policies and trainings

GOAL 3: **Data will indicate 10% of CSHCS partner organizations will advance to the next level on the Current Assessment of HCT Activities survey from their baseline by 2025.**

[3] https://www.childhealthdata.org/learn-about-the-nsch/NSCH

Step 3: Replicate the HCT assessment survey with other partner organizations such as Medicaid Health Plans (MHPs), providers and school-based health clinics.

In 2022, the MDHHS-CSHCS Program, in collaboration with staff from Got Transition® developed the first annual LHD-HCT assessment survey tool, which is designed to assess the current level of HCT activity performed by Michigan's 45 Local Health Departments (LHDs). The survey results are intended to be used to inform future program improvement initiatives both at the LHD and state-wide levels.

MDHHS CSHCS selected the Michigan State University Institute for Health Policy (MSU-IHP) to provide technical assistance and support for this project. Staff from both CSHCS and MSU-IHP were brought together to form the CSHCS HCT Survey Team (CSHCS-HCTST) to further refine the survey tool, format, and method, and to identify potential opportunities and barriers to survey implementation.

The CSHCS-HCTST asked interested members of the CSHCS Local Advisory Committee (CLAC) to review the final CSHCS LHD-HCT Survey Tool and to provide additional guidance, if any, for the proposed survey process. No further recommendations were received from the CLAC.

Survey Instrument Description

The electronic survey was formatted using the Qualtrics® [4] online survey platform and was comprised of six (6) multiple choice and one (1) free-text response questions. (Appendix B).

The multiple-choice questions were based on those found in the original *The Six Core Elements of Health Care Transition*™ survey tool and, with the permission of the *Got Transition*® staff, were modified by the CSHCS-HCTST team. For each multiple-choice question, responding LHDs were asked to select the level of activity which best described their own activity regarding key components of the health care transition process, Level 1 being the most basic, and Level 4, the most comprehensive.

The six questions explored activities related to the following HCT components:

1. CSHCS Transition Policy
2. CHSHC HCT Tracking and Monitoring
3. Transition Readiness Assessment Tools

[4] Qualtrics is a web-based survey tool used to build, conduct, and analyze surveys. More information about Qualtrics can be found at https://www.qualtrics.com

4. Transition Planning
5. Transfer of Care
6. Transition Completion

Using a free text format, respondents were also given the opportunity to share any suggestions or challenges they may have encountered regarding CSHCS transition policies, documents, and trainings.

Survey Distribution & Response Rate

Distribution Methodology

In August 2022, MDHHS-CSHCS leadership emailed 45 previously identified key staff members at each of Michigan's local health departments, asking them to complete the *2022 LHD-CC Program Assessment of Health Care Transition Activities for YSHCN* survey electronically, using the Qualtrics® online survey platform. The survey tool was accompanied by an introductory email **(Appendix F)**. In some cases, two or more local health departments manage their CSHCS activities from the same location. For these LHDs, only one survey response was elicited. It was recommended that survey respondents discuss and complete the assessment with their respective CSHCS care coordination team prior to preparing their response.

Survey Response Rate

The survey link remained open for 17 business days prior to closing. Four (4) reminders **(Appendix G)** to complete the survey were sent by email at regular intervals throughout the survey period. Survey respondents did not report difficulties accessing or completing the survey. Forty-five (45) LHD staff received the link to complete the *2022 LHD-CC Program Assessment of Health Care Transition Activities for YSHCN* survey on-line and all 45 LHD staff responded, resulting in a 100% survey completion rate. All 45 LHDs responded to each of the six (6) multiple choice questions and 39 LHDs offered free text comments and suggestions.

LHD-HCT Activities Assessment Survey Findings

In August 2022, the State of Michigan Children's Special Health Care Services (CSHCS) program conducted a survey of all LHDs regarding their Transition to Adulthood activities and the implementation of the Six Core Elements of Health Care Transition (HCT). This survey assessment was intended to provide baseline data related to each LHD's current HCT activities as well as provide ways the LHD can implement more comprehensive activities.

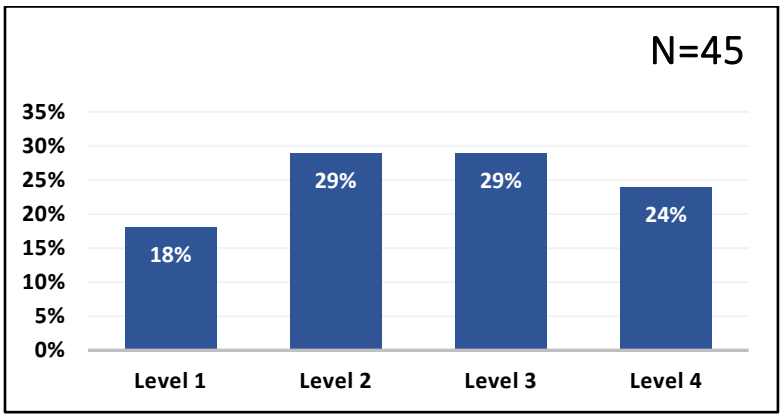
The following section summarizes the LHD's responses to questions about their activities related to transition policy, tracking and monitoring transition activities, transition-readiness assessment tools, transition planning, transfer of care to adult providers and HCT program evaluation. A summary of free-text comments and suggestions is also provided.

Each of the survey's six (6) multiple choice questions, and the possible responses, appear below. For each question, the respective activities characteristic of response Levels one (1) through four (4) are progressively more robust, culminating in the most comprehensive approach to HCT activities, e.g., Level 4. The figure below each question shows the percent of LHDs selecting each level, respectively.

Question 1: Please select the level that would best describe your LHD's CSHCS Transition Policy.

- ***Level 1.*** Care coordinators follow a similar approach to HCT but do not have a written policy.
- ***Level 2.*** The care coordination program has a written HCT policy that describes its HCT approach, legal changes that take place in privacy and consent at the age of 18 and the age when Title V eligibility ends.
- ***Level 3.*** The care coordination program has a written HCT policy that describes its HCT approach, legal changes that take place in privacy and consent at the age of 18 and the age when Title V eligibility ends. Care coordinators consistently discuss HCT with all YSHCN and their families, beginning at ages 12 to 14.
- ***Level 4:*** The care coordination program has a written HCT policy that describes its HCT approach, legal changes that take place in privacy and consent at the age of 18 and the age when Title V eligibility ends. Care coordinators consistently discuss HCT with all YSHCN and their families, beginning at ages 12 to 14. The transition policy also describes the facilitation of additional transition to adulthood domains including work and independence.

FIGURE 1: LHDs Overall Selected Levels Related to CSHCS Transition Policy

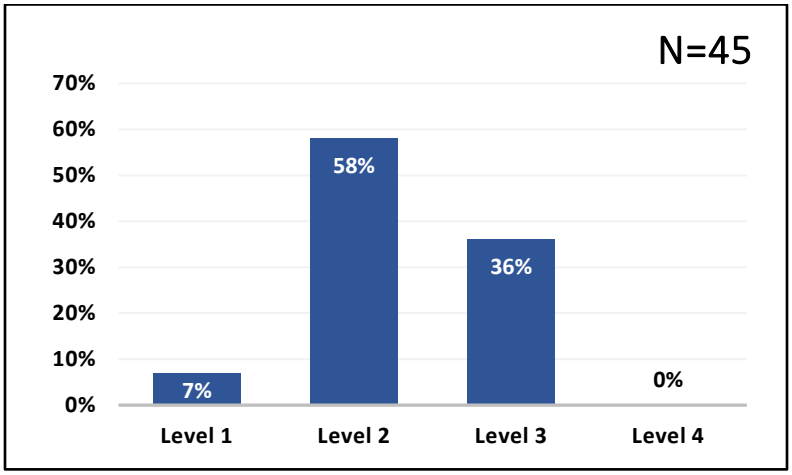


Overall, 29% of LHDs reported having a written HCT policy that describes its HCT approach, legal changes that take place in privacy and consent at the age of 18 and the age when Title V eligibility ends. Twenty-nine percent (29%) also reported that care coordinators consistently discuss HCT with all YSHCN and their families, beginning at ages 12 to 14. Fewer (24%) reported their transition policy also describes the facilitation of additional transition to adulthood domains including work and independence. Of the 45 LHDs responding to the survey,18% reported that care coordinators follow a similar approach to HCT but that there is no written policy in place (Figure 1, above).

Question 2: Please select the level that would best describe your LHD's CSHCS HCT Tracking and Monitoring.

- ***Level 1.*** Care coordinators vary in the identification of transition aged YSHCN, but most wait until close to the age of transfer to prepare youth for HCT.
- ***Level 2.*** Care coordinators use client records to document relevant HCT information (ex: discussed transition, date of transfer to adult doctor).
- ***Level 3.*** The care coordination program uses an individual transition tracking system for identifying and tracking a subset of transition-age YSHCN, ages 14 and older, as they complete some but not all the Six Core Elements of HCT.
- ***Level 4.*** The care coordination program uses an individual transition tracking system for identifying and tracking all transition aged YSHCN, ages 14 and older as they complete all the Six Core Elements of HCT.

FIGURE 2: LHDs Overall Selected Levels Related to Tracking and Monitoring HCT Activities

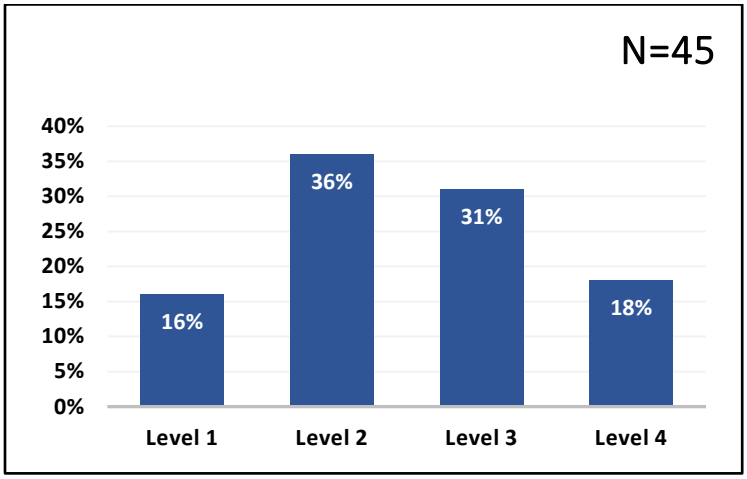


Most LHDs (58%) reported care coordinators use client records to document relevant HCT information (e.g., discussed transition, date of transfer to adult doctor), while 36% reported using an individual transition tracking system for identifying and tracking a subset of transition-age YSHCN, ages 14 and older, as they complete some, but not all, of the Six Core Elements of HCT. Seven percent (7%) of the LHDs reported Level 1 activity, compared with none reporting Level 4 activity (Figure 2, above).

Question 3: Please select the level that would best describe your LHD's CSHCS Transition Readiness assessment tools used in identifying the needs of YSHCN and their families.

- ***Level 1.*** Care coordinators vary in whether they assess HCT readiness/self-care skills.
- ***Level 2.*** Care coordinators assess HCT readiness/self-care skills but do not consistently use a HCT readiness assessment tool.
- ***Level 3.*** Care coordinators assess HCT readiness/self-care skills using a HCT readiness/self-care skill assessment tool.
- ***Level 4:*** Care coordinators consistently assess and re-assess each year HCT readiness/self-care skills, starting at ages 14 to 16, using a transition readiness/self-care assessment tool.

FIGURE 3: LHDs Overall Selected Levels Related to Transition Readiness Assessment Tools



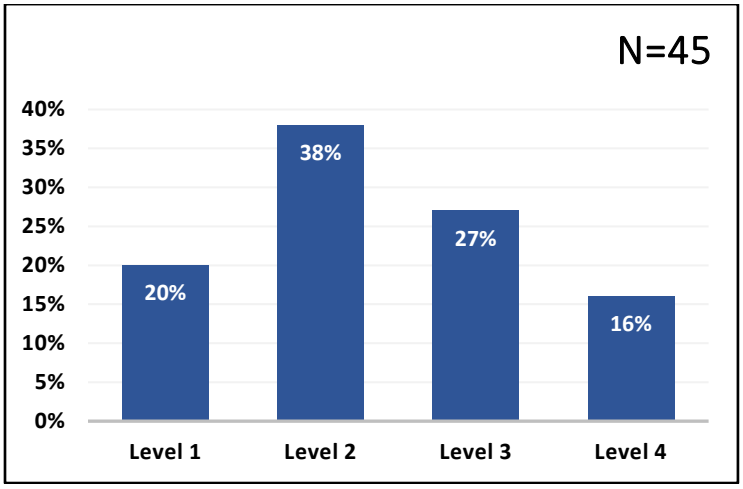
While 16% of LHDs reported care coordinators vary in whether they assess HCT readiness/self-care skills, most (36%) reported care coordinators assess HCT readiness/self-care skills but do not consistently use a HCT readiness assessment tool. By comparison, 31% of the LHDs reported care coordinators consistently evaluate readiness/self-care skills using a tool designed for this purpose. Additionally, eighteen percent (18%) of LHDs reported care coordinators consistently perform annual HCT readiness/self-care skills starting at ages 14-16 years using an assessment tool (Figure 3, above).

Question 4. Please select the level that would best describe your LHD's CSHCS Transition Planning.

- ***Level 1.*** Care coordinators vary in whether they include goals and action steps related to HCT in the plan of care for YSHCN.
- ***Level 2.*** Care coordinators consistently include goals and action steps related to HCT for YSHCN but vary in addressing privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused healthcare.
- ***Level 3.*** Care coordinators consistently include goals and action steps related to HCT for YSHCN based on the results from a HCT readiness assessment tool. Care Coordinators consistently address privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care. The plan of care is regularly updated.
- ***Level 4.*** The care coordinator program has incorporated HCT into its plan of care template for all YSHCN. Care coordinators consistently include goals and action steps related to HCT for YSHCN based on the results from a HCT readiness assessment tool. Care coordinators consistently address privacy and consent

changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care. The plan of care is regularly updated and shared with YSHCN and families.

Figure 4: LHDs Overall Selected Levels Related to CSHCS Transition Planning



Twenty percent (20%) of LHDs reported variation among care coordinators efforts to include goals and action steps in the plan of care for YSHCN. Most LHDs (38%) reported care coordinators consistently include goals and action steps related to HCT for YSHCN but vary in addressing privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused healthcare. Twenty-seven percent (27%) reported basing goals and action steps on the results of a readiness assessment tool, addressing consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care, and regularly updating the plan of care. Only 16% LHDs also reported that the plan of care is shared with YSHCN and their families (Figure 4, above).

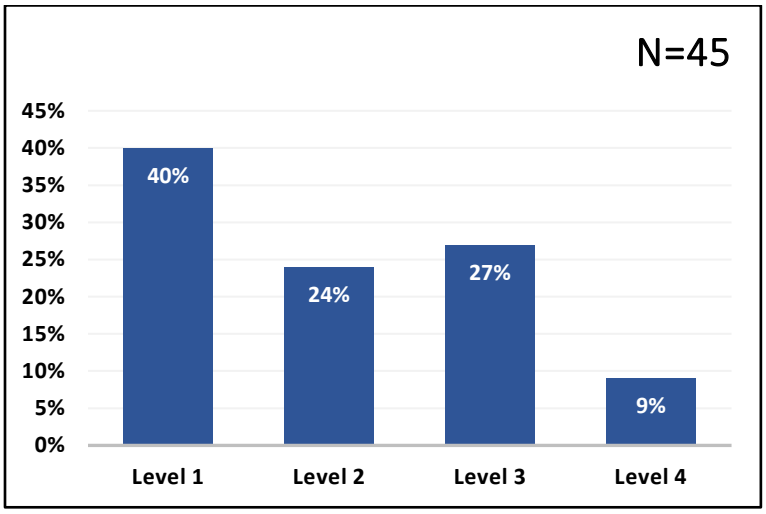
Question 5. Please select the level that would best describe your LHD's activities related to Transfer of Care to adult providers for CSHCS clients.

- ***Level 1.*** Care coordinators vary in whether they provide YSHCN and families with resources to find adult providers. They rarely share plans of care with HCT information to adult providers for their transitioning YSHCN.
- ***Level 2.*** Care coordinators consistently provide YSHCN and families with resources to find adult providers and share plans of care with HCT information to adult providers for their transitioning YSHCN. Care coordinators vary in whether they include goals and action steps related to transfer of care to adult providers in the plan of care for YSHCN.
- ***Level 3.*** Care coordinators consistently provide YSHCN and families with resources to find adult providers and share plans of care with HCT information to

adult providers for their transitioning YSHCN. Care coordinators include goals and action steps related to transfer of care to adult providers in the plan of care for YSHCN.

- ***Level 4.*** Care coordinators consistently provide YSHCN and families with resources to find adult providers and share the plan of care with HCT information to adult providers for their transitioning YSHCN. Care coordinators include goals and action steps related to transfer of care to adult providers in the plan of care for YSHCN. In addition, care coordinators routinely communicate with the youth or family that transfer of care to adult providers was completed.

Figure 5: LHDs Overall Selected Levels Related to Transferring Care to Adult Providers

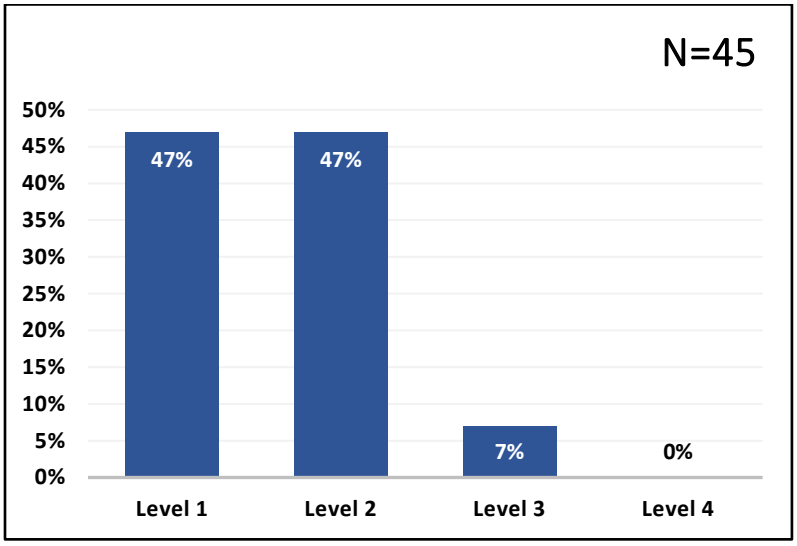


Survey data indicated that 40% of the LHD respondents reported variation among care coordinators regarding providing resources to YSHCN and their families about how to find adult care providers, and rarely share plans of care with HCT information to adult providers for their transitioning YSHCN. Although 24% LHDs reported that care coordinators consistently share plans of care and HCT information to adult providers, the same care coordinators varied as to whether they included goals and action steps related to transfer of care to adult providers in the plan of care. By comparison, 27% overall reported they both share care plans and include goals and action steps in the plan of care. In addition to these two activities, only nine percent (9%) LHDs overall reported also routinely communicating with the youth or family that transfer of care to adult providers was completed (Figure 5, above).

Question 6. Please select the level that would best describe your LHD's activities regarding HCT program evaluations for CSHCS clients that are of Transition Completion age.

- ***Level 1.*** Care coordinators vary in whether they follow-up with YSHCN and parents/caregivers about the HCT support provided by the care coordinator program.
- ***Level 2.*** Care coordinators consistently encourage YSHCN and parents/caregivers to provide feedback about the HCT support provided by the care coordination program, but do not use a specific HCT feedback survey.
- ***Level 3.*** Care coordinators consistently obtain feedback from YSHCN and parents/caregivers using a HCT feedback survey.
- ***Level 4.*** Care coordinators consistently obtain feedback from YSHCN and parents/caregivers using a HCT feedback survey and use the results as part of its transition performance measurement for the Title V block grant reporting.

Figure 6: LHDs HCT Program Evaluation for Clients of Transition Completion Age

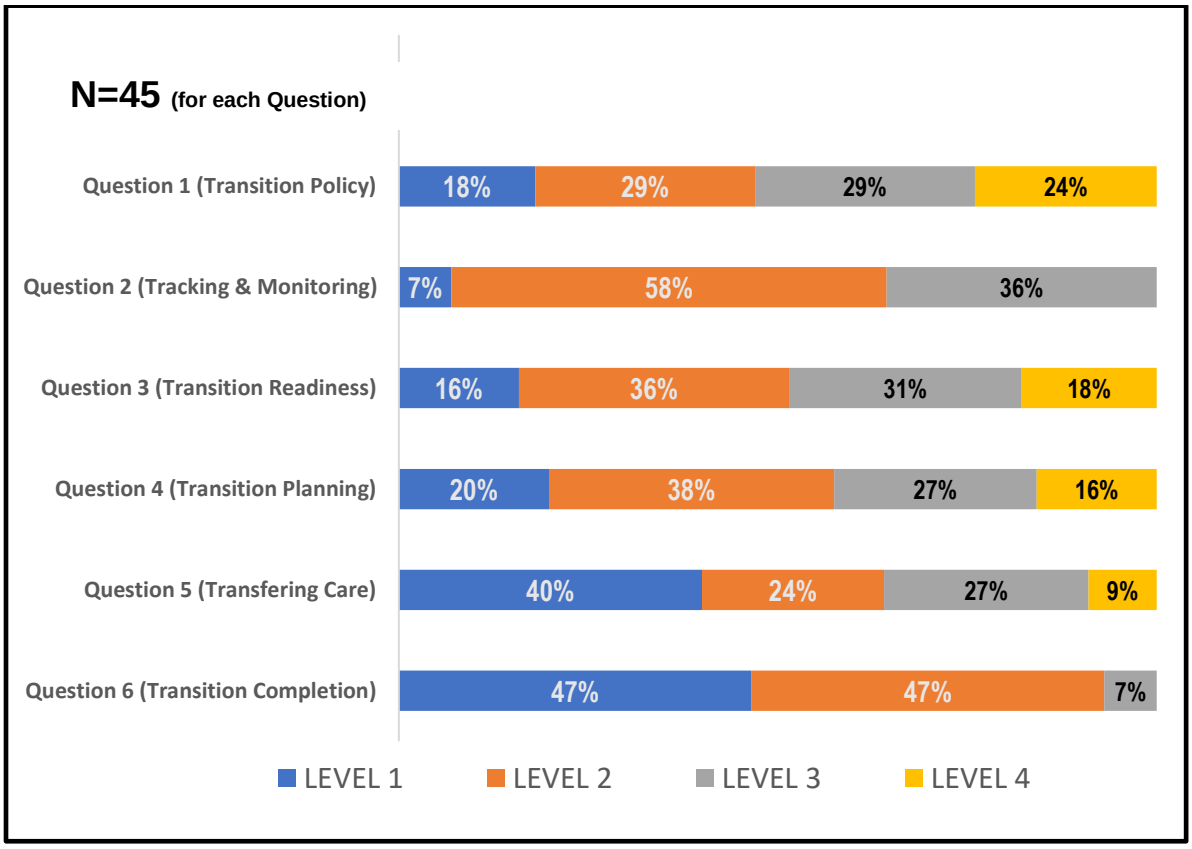


Of the 45 LHD respondents, none (0) reported consistently obtaining YSHCN and parents/caregivers' feedback through use of a HCT feedback survey or using the results as part of its transition performance measurement for the Title V block grant reporting. Furthermore, only 7% of LHDs reported that care coordinators consistently obtain feedback from YSHCN and parents/caregivers using a HCT feedback survey. Nearly half (47%) of the surveyed LHDs reported that care coordinators vary in whether they follow-up with YSHCN and parents/caregivers about the HCT support provided by the care coordinator program. Similarly, nearly half (47%) reported care coordinators consistently encourage YSHCN and parents/caregivers to provide feedback about the HCT support provided by the care coordination program, but do not use a specific HCT feedback survey (Figure 6, above).

Calculations and Methods

Figure 7 (below) shows the percentage of LHDs selecting Levels 1, 2, 3, and 4, respectively, in response to each of the questions related to the Six Core Elements. The percentage for each level was calculated using the number of LHDs who responded to each level, (x), divided by the total number of respondents (x/45). For example, if nine (9) LHDs selected Level 1 in response to a particular question, 9/45 = 20%. Note that none of the 45 LHDs selected Level 4 when responding to Question 2 or Question 6.

Figure 7: Selected Activity Levels 1 through 4 for Questions 1 through 6*



*Note: Percentages used in Figure 7 for some questions do not total 100 due to rounding.

All 45 LHDs responded to Questions 1 through 6, for a total of 270 responses. Of these, 66 Level 1, 104 Level 2, 70 Level 3, and 30 Level 4 responses were received. The number of responses received for each level (x) was divided by the total number of responses received for all questions (x/270) to arrive at the percentage of responses received for each level, overall. These calculations account, respectively, for 24%, 39%, 26%, and 11% of LHDs selecting each level, across all questions (Table 1, below).

TABLE 1: Number of Responses Received for Each Question, by Level

	Question 1 Transition Policy	Question 2 Tracking & Monitoring	Question 3 Transition Readiness	Question 4 Transition Planning	Question 5 Transfer of Care	Question 6 Transition Completion	Number of Responses to Questions 1-6 By Level (x)	Percentage Overall for Levels 1 – 4 (x/270)
Level 1	8	3	7	9	18	21	**66**	**24%**
Level 2	13	26	16	17	11	21	**104**	**39%**
Level 3	13	16	14	12	12	3	**70**	**26%**
Level 4	11	0	8	7	4	0	**30**	**11%**
Column Totals	**N=45**	**N=45**	**N=45**	**N=45**	**N=45**	**N=45**	**N=270**	**100%**

The levels selected by each of the 45 LHDs in response to questions one (1) through six (6), respectively, were totaled and then averaged (N/45) to arrive at an overall average response level for each question. The averaged responses for each of the six questions were then totaled (13.4) and divided by the number of questions (13.4/6) to arrive at an average level of activity across all six questions. Overall, LHDs scored an average of 2.23 (Level 2) for their implementation of the Six Core Elements of HCT (Table 2, below).

Table 2: Overall Average of LHD Selected Levels of Activity by Question

	Question 1 Transition Policy	Question 2 Tracking & Monitoring	Question 3 Transition Readiness	Question 4 Transition Planning	Question 5 Transfer of Care	Question 6 Transition Completion	TOTALS
Selected Levels Total by Question (N)	117	103	113	107	92	72	**604**
Overall Avg of Selected Levels Total by Question (N/45)	2.60	2.30	2.50	2.40	2.0	1.60	**13.4**
LHD's Overall Average Score for Implementation of the Six Core Elements of HCT							**2.23 (13.4/6)**

Free Text Responses: Themes, Challenges and Opportunities

When asked to share any suggestions or challenges they may have related to CSHCS transition policies, documents, and trainings, 86% (n=39) provided free-text responses. In the outline that follows, these responses have been arranged according to theme. Opportunities for program development and improvement are also identified.

THEME 1: General Management/Approach to Transition Planning

- **OPPORTUNITY:** Provide further instruction/direction about how to manage Private Duty Nursing (PDN) transitions at age 21 as well as for further training on transition and what are the expectations for transitioning clients.

THEME 2: Other Types of Transitions to Consider

- **OPPORTUNITIES**
    1. To address transition related to schooling, beginning in a pre-primary program, transitioning along the continuum of elementary, middle, junior high and high school, and completing and submitting necessary documentation to ensure the child's needs will be met at the receiving school.
    2. Provide information about how to transition clients who require private duty nursing (PDN).

THEME 3: Policy & Procedure

- **OPPORTUNITIES**
    1. Ensure new staff are given time and resources to learn policies and procedures.
    2. Staffing challenges have impeded development of specific transition processes.
    3. Guidance related to procedures and tools to help LHDs move to the highest level possible.
    4. HCT readiness tool is not currently used annually by some LHDs. In some cases, it is used once and then needs are reviewed during a Plan of Care (POC) visit.

THEME 4: Age-related Comments and Suggestions

- **OPPORTUNITIES**
    1. Currently there is a wide variation among LHDs as to how old clients should be to begin transition planning activities. Generally, LHDs most often cited ages 16-17 as most appropriate.

2. Different steps of transition should be addressed at different ages, beginning at age 14 through age 21 years.
3. Develop a means to track clients through the transition process, by age group, at ages 14, 16, 18, 21 years.
4. Consider providing the "Adult Authorization Form" when the child is 18 years old instead of at age 16, since the child cannot complete the form and most parents do not retain it until the child reaches age 18 years.

THEME 5: Transition Resources

- **OPPORTUNITIES**
    1. Simplify, update current transition-related documents, e.g., Transition Planning booklet, Family Resource, Transition Timeline, and other handouts. Eliminate redundancy.
    2. Modify documents according to age, condition, and acuity of the client.
    3. Develop a checklist for creating Plan of Care (POC) and monitoring progress toward meeting identified goals.
    4. Create age-specific discussion checklists.
    5. Printed Transition Planning booklets preferred over photocopied pages.
    6. Develop a Transition Toolkit containing updated standards and information about how to facilitate health care transition for our youth with special health care needs (YSHCN). The kit should include a section for local resources specific to each LHD.
    7. Develop a single location to go to that lists all transition resources and has transition website links to useful transition information and agencies.
    8. A "step by step" guide to aid in what ages to address specific transition information and the resources that are available for each step.
    9. Develop a means to track clients through the transition process by age group.

THEME 6: Training and Education for Staff and Clients

- **OPPORTUNITIES**
    1. Develop standardized, age-specific Transition Training for new and current employees, followed by periodic update/refresher training that contains information about:
        - Policies and procedures
        - Where to find needed resources and tools information
        - Types of Guardianship and how to assist parents with the process

2. Develop informational seminars/sessions for parents and youth about:
    - Transition and their role in the transition process
    - Job opportunities
    - Colleges, scholarships, and related processes

THEME 7: Current LHD Practices/What Works Well

1. Engaging parents 6 months prior to when their child reaches age 18 years.
2. Providing a list of hyperlinks and telephone numbers to assist parents with the Social Security Income (SSI), Medicaid, and guardianship processes.
3. Conducting a survey of parents and youth for their comments and suggestions, including questions about transition assistance.
4. Providing a copy of the Plan of Care (POC) to the family and/or provider(s).
5. Providing families with information and tools to support them through the process of transitioning their child to adult health care.

THEME 8: Current Challenges LHDs Experience

1. Staff transition support skills are minimal.
2. Staffing shortages impede LHDs' ability to address the Six Core Elements of Transition effectively.
3. Clients who do not respond to LHDs' outreach efforts, e.g., do not return completed documents or do not return outreach phone calls.
4. Tracking clients according to their age is difficult.
5. Staff typically address transition with the parent, not with the transitioning youth.
    - Speaking directly with young adults ages 18 – 20 is challenging due to their work or school commitments.
    - Parents continue to manage and develop the plan of care for young adults and continue to address issues such as billing or making new provider arrangements for them.
6. Some parents have difficulty "letting go" of their transitioning young adults.
7. Electronic Record System (ERS)
    - Has limited capacity to update goals and concerns
    - Is not part of the Plan of Care (POC) making it necessary for additional documentation steps which are difficult to update.
8. Assessment of transition readiness is a part of the Plan of Care interview.

9. The State of Michigan continues to send out the previous version of the *Over-18 Release of Information* document that requires a witness signature. Most parents sign as the witness which makes the form invalid.

Summary of Findings

The first annual, 2022 LHD-HCT Activities Assessment was conducted from August 18 through September 9, 2022, with the purpose to collect baseline, self-assessment data from the 45 Local Health Departments (LHDs) about activities related to The Six Core Elements of Health Care Transition.[3] The survey response rate was 100%. It is anticipated that annual LHD reports of this kind will track both aggregate and individual LHD self-assessment data for each of the six core elements. These annual reports can be used to demonstrate both individual LHD and aggregate progress toward achieving Level 4 status for each the Six Core Elements of HCT.

Overall, LHDs achieved a level of 2.23 across all questions for activities related to the six core elements of health care transition. The most frequently reported level of activity, overall, for Questions 1 through 6 are summarized below and compared with the percentage of LHDs who selected Level 4 for the same question. The average reported Level for each activity is also given:

1. **QUESTION 1:** Twenty-nine percent (29%) of LHDs reported Level 2 or Level 3 for activities related to following a health care transition policy compared with 24% who selected Level 4. The average of all reported levels for this activity was 2.6.

2. **QUESTION 2:** Fifty-eight percent (58%) of LHDs reported Level 2 for activities related to tracking and monitoring transitioning clients. No LHDs selected Level 4 for this question. The average of all reported levels for this activity was 2.29.

3. **QUESTION 3:** Thirty-six percent (36%) of LHDs reported Level 2 activity related to assessing transition readiness, compared with 18% who reported Level 4 for this activity. The average of all reported levels for this activity was 2.5.

4. **QUESTION 4:** Thirty-eight percent (38%) of LHDs selected Level 2 activity related to their transition planning efforts. By comparison, only 16% reported Level 4 for this question. The average of all reported levels for this activity was 2.4.

5. **QUESTION 5:** Eighteen percent18% of LHDs reported Level 1 for activities related to transferring care to adult providers, whereas only nine percent (9%) reported Level 4. The average of all reported levels for this activity was 2.0.

6. **QUESTION 6:** Forty-seven percent (47%) of LHDs reported either Level 1 or Level 2 for activities related to transition completion. By comparison, none of the LHDs reported Level 4 activity for this core element. The average of all reported levels for this activity was 1.6.

The survey also provided the opportunity for LHDS to share their suggestions or comment on the challenges they experience related to the heath care transition services they provide. Among the most frequent suggestions were to:

1. Provide standardized and additional trainings on all aspects of the transition process.
2. Begin HCT activities in the later teens, ages 17-19 years.
3. Update transition resources for staff and clients.
4. Develop age-specific transition resources.

LHDs commented on several challenges they experience while providing health care transition services. Those most frequently mentioned included large staff/client ratios related to staff shortages, tracking, and connecting with clients by way of telephone or mail, and various aspects of facilitating health care transition.

CSHCS Follow-up/Action Steps

In January 2023, representatives from the MSU-IHP staff presented the aggregate results of the *2022 LHD Care Coordination Program Assessment of Health Care Transition (HCT) Activities for Youth with Special Health Care Needs (YSHCN)* survey to the CSHCS leadership team and LHD staff. The presentation contained information about survey methodology and results analysis and attendees were given the opportunity to ask questions and discuss the findings (Appendix H). Additionally, each LHD received its individual survey results which will be used as a basis for discussions between the LHD and members of the CSHCS transition leadership team.

As a result of this survey, CSHCS, in collaboration with LHDs throughout the state, are actively revising and implementing several tools and processes aimed to improving health care transition activities. These include:

1. Redesign of the transition website to make navigation easier; website content and resources were also updated.
2. Review and update of current transition documents, including:
    a. LHD Transition Checklist
    b. Sample Transition Policy
    c. Six Core Elements of HCT Quick Guide for LHDs

d. Transition Guidebook for Youth and families

3. Creation of the LHD Transition Manual is in process. This manual will provide a variety of transition tools and guidance for LHDs including an overview of HCT, areas of focus based on client age groups (12-15 yrs., 16-17 yrs., and 18-21 yrs.), private duty nursing (PDN) transition, and quality improvement (QI) recommendations. Current copies of the transition documents and transition letters used to correspond with clients/families will be included in the appendix of the manual.

4. LHD transition reports were expanded to include all CSHCS clients ages 12-21 years.

The *2022 LHD Care Coordination Program Assessment of Health Care Transition (HCT) Activities for Youth with Special Health Care Needs (YSHCN)* survey provides self-reported, baseline information about the current level of LHD activity related to the health care transition for each of Michigan's LHDs. These activities have been undertaken in an effort to improve the HCT experience for youth and families, as well as to modify and improve the tools and processes utilized by LHD staff as they facilitate HCT for the clients they serve.

APPENDICES

TITLE	DOCUMENT
APPENDIX A 2022 CSHCS-HCT Survey Distribution List	APPENDIX A - LHD-HCT Survey Dist
APPENDIX B 2022 CSHCS-HCT Survey Tool	APPENDIX B - 2022 LHD-HCT Assessment
APPENDIX C LHD-HCT Survey Overall Results Summary	APPENDIX C - LHD-HCT Survey Ove
APPENDIX D Individual LHD Brief Reports (Example)	APPENDIX D - LHD Individual Brief Repor
APPENDIX E 2022 CSHCS-HCT Survey Introductory Email with Embedded Link	APPENDIX E - Introductory Email wi
APPENDIX F Survey Completion Reminder Email	APPENDIX F - Survey Completion Reminde
APPENDIX G 2022 LHD-HCT Survey Overview Presentation	APPENDIX G - LHD-HCT Survey Ove
APPENDIX H MDHHS-CSHCS Program Staff	APPENDIX H - MDHHS CSHCS Progr
APPENDIX I Index of Figures and Tables	APPENDIX I - Index of Figures and Tables